

Measuring bereavement support needs in people bereaved during Covid-19; the adaptation and development of a bereavement support needs scale

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Background: a tale of two studies

Lack of consistency in outcomes and measures used in bereavement research and evaluation

- **Study 1:** Identified core outcomes and dimensions for designing and evaluating bereavement support interventions
- **Study 2:** Longitudinal survey of bereavement experiences during COVID-19 including Bereavement Support Needs Scale adapted from the two outcomes

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BMC Palliative Care

RESEARCH ARTICLE **Open Access**

Coping and wellbeing in bereavement: two core outcomes for evaluating bereavement support in palliative care

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PALLIATIVE MEDICINE


Original Article

Support needs and barriers to accessing support: Baseline results of a mixed-methods national survey of people bereaved during the COVID-19 pandemic

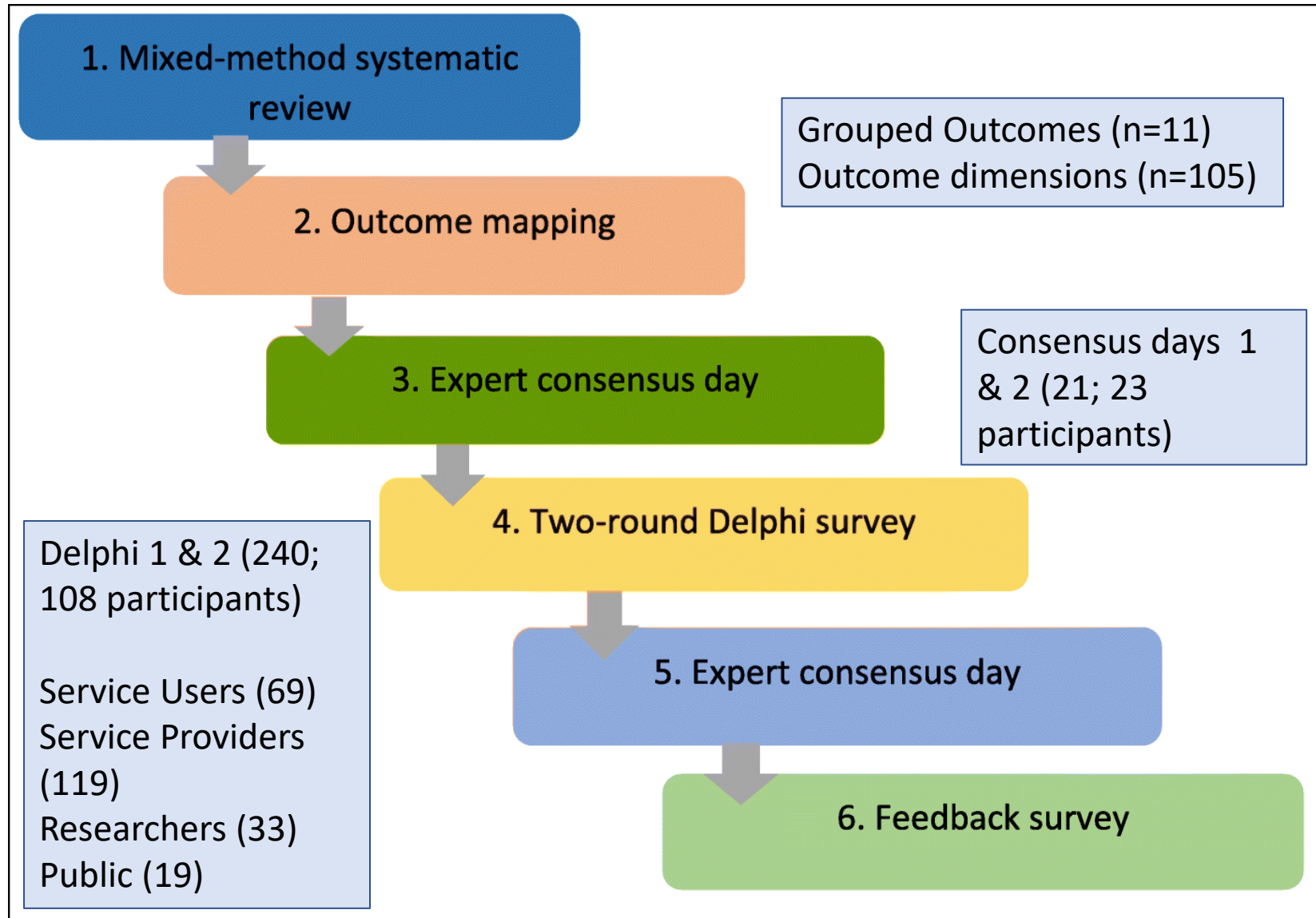
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Selecting Core Outcomes (Study 1)



Two core outcomes and dimensions

| 1. Ability to Cope with Grief | 2. Quality of Life and Mental Wellbeing |
|--|---|
| <p>Negative and overwhelming grief</p> <ul style="list-style-type: none"> • Feelings of loneliness and emptiness • Feelings of blame, guilt, anger, bitterness, regret • Overwhelming thoughts and/or nightmares about loss • Preoccupation with thoughts of the deceased | <p>Participation in work and/or other regular activities</p> <ul style="list-style-type: none"> • Ability to perform daily tasks • Ability to participate in work • Ability to participate in social activities |
| <p>Communication and connectedness</p> <ul style="list-style-type: none"> • Ability to express feelings openly and honestly • Feeling understood and connected with other bereaved people | <p>Relationships and social functioning</p> <ul style="list-style-type: none"> • Ability to function as part of a family • Relationships with friends and family |
| <p>Understanding, accepting and finding meaning in grief</p> <ul style="list-style-type: none"> • Acceptance of grief experiences as normal • Understanding, acceptance, finding meaning in loss • Positive reminiscence and remembering of the deceased | <p>Positive mental wellbeing</p> <ul style="list-style-type: none"> • Sense of meaning and purpose in life • Optimism and hopefulness |
| <p>Finding balance between grief and life going forwards</p> <ul style="list-style-type: none"> • Ability to find balance and channel grief • Ability to take control/ look ahead and move forwards | <p>Negative mental & emotional state</p> <ul style="list-style-type: none"> • Anxiety (feelings of tension, nervousness, panic and distress) • Depression (a sense of hopelessness, pessimism, periods of crying) • Suicidal thoughts |
| <p>Accessing appropriate support</p> <ul style="list-style-type: none"> • Accessing emotional support if needed • Accessing practical support if needed | |

Study 2: Bereavement experiences during Covid-19

- Aim (WP1): Document the grief experiences, support needs and use of bereavement support by people bereaved during the COVID-19 pandemic
 - Longitudinal online survey of people bereaved from 16 March 2020-5th Jan 2021 in UK (n=711)
- Baseline survey:
 - End of life & mourning experiences (e.g. restricted funerals)
 - Support Use Questions (type of support used and barriers)
 - Adult Attitude to Grief Scale
 - Support Needs Scale
- Two stage piloting; 16 members of the public with bereavement experiences



Q. Over the last three months have you needed support with the following?

| Scoring: High level / Fairly high/ Moderate/ Little/ No support needed |
|---|
| 1. Practical tasks e.g. managing the funeral, registering the death, other paperwork etc. |
| 2. Getting relevant information and advice e.g. legal, financial, available support |
| 3. Looking after myself/family e.g. getting food, medication, childcare |
| 4. Dealing with my feelings about being without my loved one |
| 5. Dealing with my feelings about the way my loved one died |
| 6. Expressing my feelings and feeling understood by others |
| 7. Feeling comforted and reassured |
| 8. Loneliness and social isolation |
| 9. Managing and maintaining my relationships with friends and family |
| 10. Finding balance between grieving and other areas of life |
| 11. Participating in work, leisure or other regular activities (e.g. shopping, housework) |
| 12. Feelings of anxiety and depression |
| 13. Regaining sense of purpose and meaning in life |

Preliminary validation & scoring

Validation

- Exploratory factor analysis confirmed two subscales (emotional support and practical support) (based on 532 participants in interim baseline data-set)
- Cronbach's α = 0.79 (for practical) and 0.95 (for emotional) subscales and 0.94 overall, indicating high levels of reliability/internal consistency.

Scoring

- Subscale scores found by determining the mean across all items in a given subscale. Overall mean is evaluated over all 13 items.
- Results for both subscale scores and the overall mean score: 1 = no support needed; 3 = moderate level of support needed; 5 = high level of support needed.

Total interim sample (n=532):

- **Person who died:** 60% parents, 19% partners/husbands, 9% grandparents
- **Cause of death:** 46% Covid-19; 20% Cancer
- **Gender:** 91% female, 8% male, 1% other/prefer not to say
- **Ethnicity:** 17 participants (3 %) from minority ethnic backgrounds
- **Age:** mean = 48.3 years (median=49 years, Range = 18 to 88)

| Baseline (n=711) | High/fairly high level of support needed | Moderate level of support needed | Little or no support needed | Mean (95% CI) | Median |
|--|--|----------------------------------|-----------------------------|---------------------|--------|
| Dealing with my feelings about the way my loved one died | 59.8% | 21.5% | 18.7% | 3.71 (3.62 to 3.80) | 4 |
| Dealing with my feelings about being without my loved one | 49.9% | 29.3% | 20.8% | 3.48 (3.39 to 3.57) | 3 |
| Expressing my feelings and feeling understood by others | 53% | 23.9% | 23% | 3.48 (3.38 to 3.57) | 4 |
| Feeling comforted and reassured | 51.8% | 26.7% | 21.6% | 3.46 (3.37 to 3.55) | 4 |
| Feelings of anxiety and depression | 52.8% | 21.1% | 26.1% | 3.45 (3.35 to 3.55) | 4 |
| Loneliness and social isolation | 52.0% | 19.1% | 29% | 3.36 (3.26 to 3.46) | 4 |
| Finding balance between grieving and other areas of life | 45.0% | 27.9% | 27% | 3.29 (3.20 to 3.39) | 3 |
| Regaining sense of purpose and meaning in life | 46.7% | 21.6% | 31.7% | 3.26 (3.15 to 3.36) | 3 |
| Managing and maintaining my relationships with friends and family | 36.2% | 26.4% | 37.4% | 2.98 (2.88 to 3.08) | 3 |
| Participating in work, leisure or other regular activities | 33.8% | 23.9% | 42.1% | 2.87 (2.76 to 2.97) | 3 |
| Getting relevant information and advice e.g. legal, financial, support | 24.3% | 22.3% | 53.3% | 2.51 (2.41 to 2.61) | 2 |
| Practical tasks e.g. managing the funeral, registering the death | 23.5% | 21.7% | 54.7% | 2.48 (2.38 to 2.58) | 2 |
| Looking after myself/family e.g. getting food, medication, childcare | 15.2% | 22.8% | 62% | 2.25 (2.16 to 2.34) | 2 |

Scale and sub-scale scores

- Scores calculated and compared for scale and sub-scales;

Overall support, mean = 3.12 (95% CI = 3.04 to 3.19), i.e. moderate level of support needed overall

Emotional subscale, mean = 3.33 (95% CI = 3.25 to 3.41), i.e. moderate level of emotional support needed.

Practical subscale, mean = 2.41 (95% CI = 2.34 to 2.50), i.e. little practical support needed

Results for the emotional subscale were significantly higher than for the practical subscale

- Factors associated with higher levels of support need*;

Close relationships with the deceased (versus more distant e.g. loss of child or partner)

Reported social isolation and loneliness

Reduced support from health professionals after death

*Selman et al. 2022 [Factors associated with higher levels of grief and support needs among people bereaved during the pandemic: Results from a national online survey | medRxiv](#)

Conclusion and future work

- Novel and pragmatic adaptation of an outcome set intended for use in the design and evaluation of bereavement interventions
- Scales demonstrated good reliability and internal consistency
- Inform policy and practice by highlighting specific domains where support needs are highest, and identify variations across demographic and clinical groups
- Tailoring of personalised support e.g. need for formal therapeutic support or social support/companionship interventions
- Future work –secondary analysis to explore group differences on specific items and corresponding free text survey data

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For study papers, see: www.covidbereavement.com/reports-and-publications